

## Preventing Fetal Alcohol Spectrum Disorders (FASD)

Satellite Conference  
Thursday, March 2, 2006  
2:00 - 4:00 p.m. (Central Time)

Produced by the Alabama Department of Public Health  
Video Communications and Distance Learning Division



### Faculty

Kathleen Mitchell, MHS, LCADC  
Vice President and National Spokesperson  
National Organization on Fetal  
Alcohol Syndrome (NOFAS)  
Emory Regional Training Center  
Atlanta, Georgia

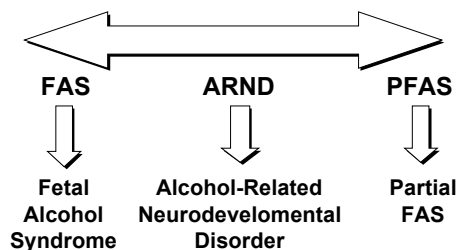
### Program Objectives

- Identify the specific criteria for diagnosis of Fetal Alcohol Syndrome (FAS) and understand how timing and dosing of prenatal alcohol can affect fetal development.
- Gain knowledge of behaviors and disorders that are consistent with individual with FASD.

### Program Objectives

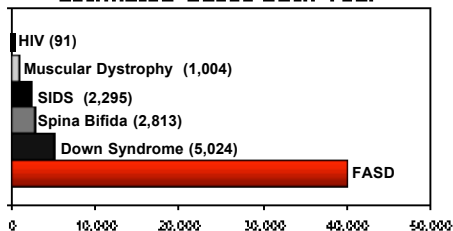
- Gain knowledge of biological, social, and environmental differences in identifying and treating substance-abusing women.
- Identify techniques for assessing, intervening and engaging addicted women into the healing process.
- Discuss how families that give birth to children with FASD are affected.

### Fetal Alcohol Spectrum Disorders



## 40,000 New Cases of FASD Annually

Estimated Cases Each Year



## Costs of FAS

- FAS costs U.S. \$5.4 billion annually.
- An FAS birth carries lifetime health costs of \$860,000, although can be as high as \$4.2 million.
- Including quality of life, FAS prevention may be “cost effective” at up to \$850,000 per child.
- 1 in 100 births in the U.S. will have effects from exposure to alcohol .

## NOFAS Vision

- The vision of the National Organization on Fetal Alcohol Syndrome (NOFAS) is a global community free of alcohol-exposed pregnancies and a society supportive of individuals already living with Fetal Alcohol Spectrum Disorders (FASD).

## NOFAS Mission

- The National Organization on Fetal Alcohol Syndrome (NOFAS) is the leading voice and resource of the Fetal Alcohol Spectrum Disorders (FASD) community. NOFAS, the only international FASD non-profit organization, is committed to prevention, advocacy and support.

## NOFAS Mission

- NOFAS effectively increases public awareness and mobilizes grassroots action in diverse communities and represents the interests of persons with FASD and their caregivers as the liaison to researchers and policymakers. By ensuring that FASD is broadly recognized as a developmental disability, NOFAS strives to reduce the stigma and improve the quality of life for affected individuals and families.

## What Does NOFAS Provide?

- Public Awareness
  - Media Outreach
  - PSA
  - Awareness Campaigns
  - Youth Education
- Professional Education
  - Curricula
  - Provider training

**[www.nofas.org](http://www.nofas.org)**

## What Does NOFAS Provide?

- Advocacy
  - Government Affairs
  - Advisory
- Constituent Services
  - Affiliate Network
  - Birth Mom Network
  - Support Groups
  - Consultation
  - Referral

[www.nofas.org](http://www.nofas.org)

## Website, Newsletters, PSA's, Posters & Fact Sheets



[www.nofas.org](http://www.nofas.org)



**Mission Statement**  
The mission of the Circle of Hope is to increase understanding and support and strengthen recovery for women who drank during their pregnancy(s), and their families.



**Goals**  
Improve and strengthen the lives of birth families. Provide peer support for birth families. Decrease the stigma, blame and shame that birth families may experience.

## Substance Use in Pregnancy

- Overall rates of alcohol use among pregnant women have declined since 1995. But rates of frequent and binge drinking remain at high levels.
- More than 130,000 pregnant women per year in the U.S. consume alcohol at risk levels.

## Substance Use in Pregnancy

- 1 in 30 women who know they are pregnant reports "risk drinking".
- 1 in 7 women of childbearing age engage in "risk drinking".
  - Birth defects associated with alcohol exposure can occur before a woman knows she is pregnant.
  - Nearly 50% pregnancies are unplanned.

## 2 Things Necessary for Life:

- Water
- Women

- **Myth:**
  - An addict will not go into treatment until they have hit bottom.
- **Truth:**
  - An addict lives on an emotional bottom, we just need to take the time to tell them.

### Women Identify the Top Three Barriers to Addiction Treatment

- 39% said the inability to admit the problem is severe enough to warrant treatment (denial).
- 32% said the lack of emotional support for treatment from family members.
- 28% inability to provide adequate care for children.

2002 Caron Foundation [www.womenhealing.org](http://www.womenhealing.org)

### Women and Treatment

- Women receive the most benefit from treatment programs that provide comprehensive services for meeting their basic needs including access to:
  - Food, clothing, shelter
  - Transportation
  - Employment/vocational counseling
  - Legal assistance
  - Literacy training and educational opportunities
  - Child care
  - Social services

### Identifying Alcoholism in Women:

- **Family History:** genetic susceptibility.
- **Tolerance:** The need to drink greater amounts of alcohol in order to “get high.”

### Identifying Alcoholism in Women:

- **Physical dependence:** Withdrawal symptoms, such as nausea, sweating, shakiness, and anxiety, occur when alcohol use is stopped after a period of heavy drinking.
- **Major organ damage:** liver, heart, kidney, central nervous system, etc.

### Progression of Alcoholism

Stage 1 - Tolerance	Stage 2 - Physical Dependency	Stage 3 - Major Organ Change
high tolerance with occasional use	increased tolerance/possible a.m. use	possible daily or maintenance use (reduced tolerance)
occasional hangovers	withdrawal: headaches/nausea (anorexia, high BP, loss of concentration, weakness)	migraines vomiting rapid pulse, BP disorientation
disrupted sleep patterns	sleeplessness	insomnia
Colds/ infections	disease pathology developing	major organ damage
Irritability-mood swings-mild depression-isolation	MH diagnosis (depression, anxiety, panic) institutions and rx	suicidal ideation or attempts

K. Mitchell, 2004



Stage 1 Tolerance	Stage 2 Physical Dependency	Stage 3 Major Organ Change
memories of how nice use was	preoccupation/ craving	use despite consequences
one-two gateway drugs	variety of drug use	multiple drug addictions
mild tremors	intentional tremors	seizures or D.T's
sexual pleasure	sexual problems	impotence
family problems	school & work problems	loss of family, job & school
trouble with the law (close calls)	DWI-DUI / possession	incarcerations

K. Mitchell, 2004

## Women Can and Do Recover From Addictive Disease; Treatment Needs To Include the Following:

- Biological differences
- Social differences
- Co-dependency issues
- Communication problems
- Shame and secrets
- Incorporate spirituality

## Moving from Victim to Warrior Mom!



## Our Families Journey Through Addiction, Denial and Recovery



## 1977 - Karli, Danny and Erin A Happy Little Hippy Family



## Karli age 10 (diagnosed with cerebral palsy)



### **Our Family Process:**

- Years of frustration and misdiagnosis.
- Years of believing that Karli was not trying her best.
- Believing that Karli would “grow out of it”.
- Received Diagnosis of FAS for Karli (16 years of age).

### **Acceptance Phase**

- Survival: Do or Die!
- Catapulted into Process of Recovery.

### **Karli at 16 Receives Diagnosis of FAS New House Rules:**

No discussing what Karli cannot do!  
The focus changed to what Karli could do:

- Great artist!
- Friendly to everyone.
- Wants to be helpful.
- Everyone likes Karli.
- 100% pure of heart, Holy.
- Would not hurt another person-ever!
- Really wants your approval.
- Great with the elderly and individuals with severe handicapping conditions.



### **Transformation Stage**

- Sought out spiritual healing & concepts:
  - Changed thinking from linear to circular released negativity.
  - “Breathe God in and Kathy out”.

### **Karli Possessed a Natural Ability for Spiritual Simplicity!**

- Maybe she was here to teach us??...
- The glass was now half full!!

**"We are not human beings  
having a spiritual  
experience, rather spiritual  
beings having a human  
experience."**

Pierre Teilhard de Chardin

**Support and Understanding  
From My Family Was the Key to  
My Recovery.**



**Individuals With FASD Make  
Powerful Advocates!**



**Carl Jung's theory of  
synchronicity:  
We are all connected and  
intertwined with perfect timing.  
There is a reason for  
everything.**

**There are no mistakes!**

**"Behold, thou shalt  
conceive and bear a son:  
and now drink no wine or  
strong drinks."**

- JUDGES 13:7

### **Use of Ethanol in Threatened Premature Labor**

- View on the absolute safety of alcohol in pregnancy continued into the 1960's when the alcohol drip was introduced in obstetrics.
- One of few medical uses of ethanol.
- Involved I.V. ethanol infusion for 6–10 hours, reaching BAC as high as 160 mg/dl.

– First report — Fuchs, F., et al., Am. J. Obstet. Gynecol., 99:627 (1967)

## Fetal Alcohol Syndrome

- Specific pattern of facial features.
- Pre- and/or postnatal growth deficiency.
- Evidence of central nervous system dysfunction.
- Maternal Alcohol Exposure
  - Confirmed alcohol exposure or
  - Unknown alcohol exposure

## Increased Sibling Mortality in Children with FAS

- Study compared the rate of all-cause mortality in siblings of children diagnosed with FAS with the siblings of matched controls.
- The siblings of children with FAS had increased mortality (11.4%) compared with matched controls (2.0%), a 530% increase in mortality.

## Increased Sibling Mortality in Children with FAS

- Siblings of children with FAS had increased risk of death due to infectious illness and SIDS.
- A diagnosis of FAS is an important risk marker for mortality in siblings even if they do not have FAS.
- Maternal alcoholism appears to be a useful risk marker for increased mortality risk in diagnosed cases and their siblings.

• Authors: Burd L.; Klug M.; Martsof 2004

## 2005 Surgeon General's Updated Recommendations

- Women who are pregnant should not drink.
- A woman who has already consumed alcohol during pregnancy should stop to avoid further risks.
- Women who are at risk for or are trying to become pregnant should not consume alcohol.
- Health professionals should work with all women of child bearing age to reduce risk.

## Fetal Alcohol Syndrome

- Fetal alcohol syndrome is the leading known cause of preventable mental retardation and is a leading cause of birth defects and learning and behavioral disorders.



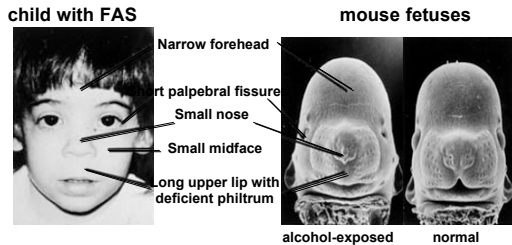
## Introduction

- Alcohol is a teratogen (def. an agent that can cause malformations of an embryo or fetus). Alcohol can cross the placenta and enter fetal circulation, damaging cells and the DNA they contain.



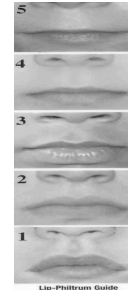


The facial features of Fetal Alcohol Syndrome can be seen in both a child and a mouse fetus that were exposed to alcohol during development



## Lip – Philtrum Guide

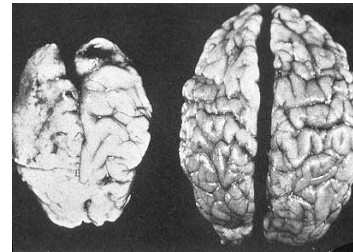
- ABC – Scores
- C- 5
- C –4
- B –3
- A – 2
- A -1
- Smooth philtrum and thin vermillion must rank 4 or 5



## Growth

- Confirmed prenatal or postnatal height or weight, or both, at or below the 10th percentile, documented at any one point in time.  
– (adjusted for age, sex, and race or ethnicity.)

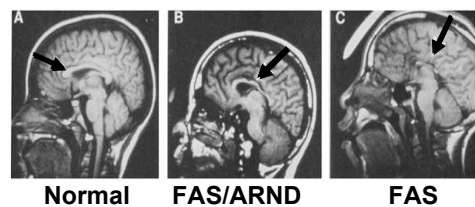
Structural head circumference at or below 10<sup>th</sup> percentile, abnormalities observable through imaging  
Neurological Functional



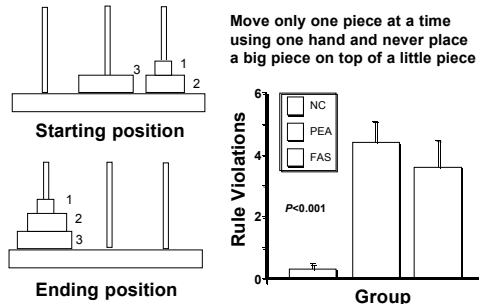
## Prenatal Exposure to Alcohol Can Cause Permanent Changes in the Brain

- These changes in the brain are not due to poor postnatal environments, being in foster care, or a host of other possibilities.
- Knowing what brain areas are involved might enable us to develop better treatment strategies.

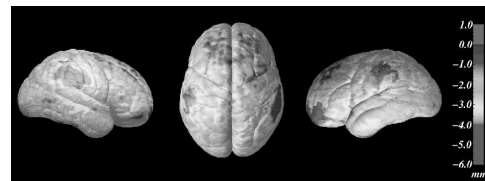
Visualization of the brain of a normal individual (A) and two with FAS (B,C) shows permanent loss of the tissue indicated by the arrows (portions of the corpus callosum).



## Executive Functioning Deficits



## Brain Shape



Area in red indicates where the brain is too small or too thin, relative to normal brain shape

## Summary of Neuropsychological Findings

- Heavy prenatal alcohol exposure is associated with a wide range of neurobehavioral deficits including visuospatial functioning, verbal and nonverbal learning, attention, and executive functioning.
- Children with and without physical features of the fetal alcohol syndrome display qualitatively similar deficits.

## Common Disorders Identified with FASD

- Autism/Aspergers' Disorder
- Attention Deficit Hyperactivity Disorder (ADHD)
- Borderline Personality Disorder
- Attachment-Bonding Disorder
- Depression
- Learning disability
- Oppositional-Defiant Disorder
- Post Traumatic Stress Disorder (PTSD)
- Receptive-Expressive Language Disorder
- Conduct Disorder

## University of Washington Fetal Alcohol and Drug Unit

In a study that examined 415 persons with FASD between the ages 6-61, Dr. Ann Streissguth found:

## Potential "Secondary Disabilities"

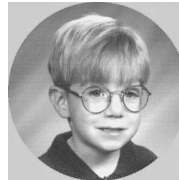
- Mental health problems (90%)
- Disruptive school experience (60%)
- Trouble with law (60%)
- Confinement (50%)
- Inappropriate sexual behavior (50%)
- Alcohol/drug problems (30%)
- Dependent living (80%)
- Employment problems (80%)



### **Systems Impacted by FASD:**

- Healthcare, insurance, HMO, MCO
- Education, (alternative/special ed)
- Justice, juvenile justice (recidivism)
- Shelters/housing
- Mental health and addiction (recidivism)
- SSI and disability
- Public assistance

### **Early diagnosis can help prevent secondary disabilities**



### **Diagnosis Prevents FASD**

- Breaking the cycle within the family
  - Reproductive health for SA women
- Global prevention

### **Individuals with FASD Have Some Degree of Brain Damage**

- Modify systems of care.
- The best parents, counselors, educators, etc., cannot will or love away brain damage.
- Accept degree of disability.

### **Be Innovative and Creative**

- Follow your intuition.
- Watch the child and learn from the messages he sends.

**Re-Think the System.**  
**How can we adapt to better serve this child?**

### **Prevention of FASD Assessment of Mothers and their Children**

- Screening
- Intervention
- Diagnosis
- Treatment





### **Key Clinical Practices**

- **Ask:**
  - All women of childbearing age about alcohol use.
  - All pregnant women about alcohol use.

### **Key Clinical Practices**

- **Advise:**
  - All women planning a pregnancy that no alcohol is the safest choice.
  - All pregnant women that no alcohol is the safest choice.
  - Women who consumed alcohol during their pregnancy to contact local resources and services.

### **Key Clinical Practices**

- **Assist:**
  - Assist women to stop drinking through information, counseling, care and referral to appropriate programs and services.

### **Opportunity**

- Pregnancy is an opportunity for change.
- Women who are pregnant are more receptive to intervention programs and treatment than women who are not currently pregnant.

### **Discuss Birth Experiences with Women**

- **Red Flags:**
  - Two or more miscarriages?
  - Stillbirths?
  - Infant/child deaths (SIDS)?
  - Children with LD, ADHD, MH or behavioral disorders?
  - Children diagnosed with FASD?
- Positive response to any of the above questions should warrant a screening of all children for possible FASD (where substance use is known or suspected).

### **TWEAK**

- **Tolerance:** How many drinks can you hold?
- **Have close friends or relatives** worried or complained about your drinking in the past year?
- **Eye-Opener:** Do you sometimes take a drink in the morning when you first get up?

### **TWEAK**

- **Amnesia:** Has a friend or family member ever told you about things you said or did while you were drinking that you could not remember?
- Do you sometimes feel the need to cut down on your drinking?

### **TWEAK**

- 7 point scale.
- Tolerance= 2 points If a woman reports she can "hold" more than five drinks without passing out.
- Positive response to the worry= 2 points.
- Last three questions = 1 point for positive responses.
- Total score of three or more points indicates the woman is likely to be a heavy/problem drinker.

### **During Screening**

- Follow up the screening questions with probes.
- Be non-judgmental.
- Listen attentively to her concerns.
- Refrain from negative comments or reactions.
- Focus on your patient as well as her baby.

### **During Screening**

- Be sensitive to broader issues and contexts such as poverty or abuse.
- Make positive statements about the woman seeking prenatal care.
- Make positive statements about progress during each visit.

### **Refer to Treatment!**

#### **Locate Treatment that Provides Feminine Focused Recovery**

**Address the unthinkable:**

- Sexuality
- Biological differences
- Menstruation
- Abuse
- Substance use during pregnancy and possible consequences
- Secrets
- Desires, dreams and fantasies

## Biological Differences

- Women's bodies have less body water than men of similar body weight.
  - Achieve higher concentrations of alcohol in the blood with equivalent amounts of alcohol.
- NIAAA Alcohol Alert 1999.

## Menstrual Cycle

- Calendar to chart bleeding, cravings, moods, behavioral reactions, depression.
- Discuss ovulation.
  - Half-way through cycle.
  - Increase in vaginal discharge.
  - Slight cramping in abdomen.
  - May augment moods.

## Women with Addictive Disease

Many have lost their voice; have turned off their "inner wisdom".

- Have low self-esteem.
- Have little self-confidence.
- Feel powerless.
- Majority have been physically and/or sexually abused.
- Are co-dependent.
- Have been living in secrecy.

## Teach Communication Skills:

I can't to I won't

Saying NO: Setting Boundaries

Assertiveness

## Empowering and Honoring the Feminine

- Intuitive wisdom.
- Motherhood / life-giving.
- Healers.
- Caretakers.
- Artisans.
- Visionaries.



## Identify or Create "Natural" Connections

- Re-connecting Women:
  - Family:
    - sisters, mothers, grandmothers, daughters, granddaughters.
  - AA/NA
    - Women's meetings, women's retreats.

## Identify or Create “Natural” Connections

- Re-connecting Women:
  - Women Circle’s/Clubs/Meetings
    - Artist way meetings, inner child groups, quilting.
  - Spiritual communities.
  - Social activities.
  - Health club/physical Activities/county recreation.
    - Art or yoga classes.

## Help Women to Change Their Belief Systems: Maybe I Could Experience Good Things in Life?

- Encourage her to nourish, giggle, hug, create, take risks, massage and to sit and listen and you will witness a Beautiful Soul Bloom!

**Hello SOUL-SELF!**

## Community Prevention

- Disseminate NOFAS brochures.
- Display NOFAS posters.
- Conduct educational and training workshops.



## Take Away Message:

- Identify women and/or their children with FASD.
- Pursue an assessment and diagnosis when signs of FASD are evident.
- Incorporate mind, body, and spiritual healing strategies for treating mothers of children with FASD.

## Take Away Message:

- Ensure that healthcare professionals are:
  - Trained to educate their clients on the effects of alcohol use during pregnancy on the developing fetus.
  - Competent in their ability to identify and appropriately pursue an assessment.
  - Understand possible treatment referrals for patients with possible FASD.
  - Discussing reproductive health options with women.



Together we can prevent FASD and create systems of care to Support individuals with FASD.

## **Upcoming Programs**

**Diabetes Update:  
Proactive Steps for Health Foot Care  
Tuesday, March 7, 2006  
2:00 - 4:00 p.m. (Central Time)**

**For complete listing of upcoming  
programs visit our website at  
[www.adph.org/alphtn](http://www.adph.org/alphtn)**